A Methodology for Surveying Disabled Persons using a Supplement to the Labour Force Survey

D. DOLSON, P. GILES, and J.-P. MORIN

ABSTRACT

In response to a need for data on disabled persons in Canada, Statistics Canada undertook a program to create a disability database. This includes using supplements to the Canadian Labour Force Survey in the Fall of 1983 and the Spring of 1984, as well as including questions on the 1986 Census of Population. A general discussion of the background and content of the survey is presented. A comparison of screening methodologies conducted by Statistics Canada in November 1982 and January 1983 is presented and the results are compared.

KEY WORDS: Disability; Screening; Activities of Daily Living.

1. INTRODUCTION

On May 23, 1980 the Canadian government created the Special Parliamentary Committee on the Disabled and the Handicapped. In February 1981 (the International Year of the Disabled) this committee published its report, entitled “Obstacles” [4]. Recommendation 113 of the “Obstacles” report reads in part:

“That the Federal Government directs Statistics Canada to give a high priority to the development and implementation of a long-term strategy which will generate comprehensive data on disabled persons in Canada, using population-based surveys and program data.”

The government, wishing to respond positively to the recommendations contained in the report, thus requested Statistics Canada to undertake a survey of disabled persons.

This paper focuses on disability surveys conducted as supplements to the Canadian Labour Force Survey (LFS) in October 1983 and June 1984 and on tests which were done in November 1982 and January 1983.

2. DEFINITIONS

Definitions developed by the World Health Organization (W.H.O.), given in McWhinnie (1980), were employed by the Special Parliamentary Committee. These definitions arise out of a model which focuses on the consequence of disease, and addresses the following illness-related phenomena.

\[
\text{DISEASE} \rightarrow \text{IMPAIRMENT} \rightarrow \text{DISABILITY} \rightarrow \text{HANDICAP}
\]
As given in World Health Organization (1980), the definitions of these terms are as follows.

**Impairment:** In the context of the health experience, it is any loss or abnormality of psychological, physiological or anatomical structure or function.

It is characterized by losses or abnormalities that may be temporary or permanent, and that include the existence of an anomaly, defect, or a loss in a limb, organ, tissue, or other structure of the body, including the systems of mental function. Impairment represents the exteriorization of a pathological state, and in principle reflects disturbances at the level of the organ.

**Disability:** It is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or in the range considered normal for a human being.

It is characterized by excesses or deficiencies of customarily expected activity, and may be temporary or permanent, reversible or irreversible, and progressive or regressive. Disabilities may arise as a direct consequence of impairment or as a response by the individual, particularly psychologically, to a physical, sensory, or other impairment. Disability represents the objectification of an impairment, and as such, it reflects disturbances at the level of the person.

**Handicap:** It is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Handicap is concerned with the value attached to an individual’s situation or experience when it departs from the norm. It is characterized by a discordance between the individual’s performance or status and the expectations of the individual himself or the particular group of which he is a member. Handicap thus represents the socialization of the impairment or disability, and as such reflects the consequences for the individual (cultural, social, economic and environmental) that stem from the presence of impairment and disability.

To explain these definitions more clearly, consider an example:

```
DISEASE    Arthritis
↓
IMPAIRMENT Inflammation of the joints in hands and fingers
↓
DISABILITY Inability to grasp and hold
↓
HANDICAP Limited in the kind or amount of work which can be done
```

3. **TARGET POPULATION**

Ideally the target population would include all persons in Canada who are disabled according to the above definition and subject to constraints on severity and duration. Severity can be regarded in terms of the person; i.e., how severely is a person disabled, or in terms of disability; i.e., how severe is the specific disability. In defining a target population, a measurement of severity must be included, if only implicitly. The duration of disability must be explicitly addressed. To capture all disabilities, including those arising out of acute illnesses of relatively limited duration, would identify a large percentage of people and run contrary to the spirit of the “Obstacles” recommendation. Nevertheless, to limit the population to the permanently disabled is avoiding the issue and ignoring the needs of the long-term but not chronically disabled.
As explained in the next section, the data were collected through the use of the supplementary capacity of the LFS. In addition to the normal constraints of the LFS, one significant limitation was imposed by the use of the LFS. The target population of the disability survey was not to include the "mentally ill". For example, the target population excluded illness such as amnesia, neuroses and phobias but included impairments of intelligence such as mental retardation or dyslexia. It was felt that asking for this information could be very sensitive in nature and negative reactions could compromise the primary objectives of the LFS.

Thus the target population for the disability survey tests includes all persons having one or more physical (nonbehavioural) disabilities, or knowledge acquisition or other educational disabilities (arising from impairments in intelligence, attention, psychomotor functions and language), whose duration has been or is expected to be at least six months. It also includes individuals suffering from diseases of a chronic and degenerative nature and which have a high probability of producing impairments which are physically disabling. In addition the normal constraints of the LFS are in effect which precludes individuals in institutions.

4. DATA COLLECTION

The difficulty is in translating the definitions into a set of questions which identify persons of interest from a set of persons in the general population. This leads to setting an objective to collect information on those who have a high probability of being disabled by any user's definition, and at the same time, keeping the number of people surveyed within reasonable limits.

The first option studied was to include questions on the Census of Population. However the diverse data requirements would have required ten to thirty additional questions, which was clearly not possible. The second option considered was to include a limited number of questions on the Census of Population, which would identify the disabled. In order to meet the data requirements, a follow-up survey would be required. In fact, this option has been approved and disability questions will be included on the 1986 Census questionnaire. This will provide detailed estimates for small areas. However, results from the follow-up survey will not be available before 1988 or 1989. Given that the current demand for data was high as well as the fact that this demand was mainly for national baseline estimates, the Census/follow-up option was considered inadequate by itself.

For meeting current data requirements, two alternatives were considered. The first possibility would be to mount on a continuous or periodic basis a household survey similar to the Canada Health Survey, to provide a profile of the disabled and handicapped. Such a survey could use survey methods designed particularly for the collection of disability data. However, resource constraints made this proposal not feasible. The second alternative was to use the supplementary capacity of the LFS. For reasons of expediency and cost, this was the method chosen. This has the secondary advantage that the resulting disability data on the individual can be directly linked to their labour force data collected by the LFS.

The data collection for the disability survey was conducted in two stages. First, all persons in all households in the LFS sample, except the one-sixth of the sample which is in its first month of the survey, underwent a "screening" process. Persons of potential interest were identified by means of a "screening" questionnaire. The mode of data collection was the same as for the LFS interview. However, the interviewers were asked to obtain non-proxy interviews as often as possible, even if it meant calling back at a later time. This "screened in" population was then asked another set of questions in a follow-up survey. All of these interviews took place about a week after the screening interview. They were all personal interviews and non-proxy responses only were accepted. This second set of questions was designed to collect the data identified as being desirable by a consultation process with the users.
The schedule for the survey was as follows. Three proposed screening questionnaires were tested in November 1982 and January 1983. More details on these surveys will be given later. Based on the results of these surveys, one screening questionnaire was developed. Two "full" surveys with a screen and a more detailed questionnaire as described above were conducted in October 1983 and in June 1984.

5. APPROACHES TO SCREENING - OTHER SURVEYS

The first step in constructing a set of screening questions was to investigate experiences encountered by other groups that had previously conducted disability surveys.

The one approach that has been used in many surveys is the Activities of Daily Living (ADL) approach. The Activities of Daily Living are a set of activities which any person is required to perform during the course of their regular living pattern. Although there is no generally recognized "best" set of activities that should be used, the set developed in 1978 by the Organization for Economic and Co-operative Development (OECD) and noted in McWhinnie (1980) has been used by surveys in several countries; see Klaukka (1981), Mizrahi and Mizrahi (1981), Raymond, Christie and Clemence (1981), Van Sonsbeek (1981), Wilson and McNeil (1981).

Since a person's ability to perform an ADL may depend on their use of a physical aid, such as an artificial limb, the use of a list of physical aids for screening could be appropriate.

Another approach for screening is that of major activity limitation. If a person is limited in his/her major activity (i.e., work, school, home) that person is probably experiencing some disability. This approach has been used in the United States in a pretest for a disability survey (1980) and in the annual Health Interview Survey, and in Canada in the Canada Health Survey (1978-79).

A list of chronic conditions could be useful for screening since persons with chronic conditions are in the target population but may be missed by ADL's or activity limitation if the person has intermittent difficulty.

Finally a person could be asked a single self-perception question such as "Do you have any physical disabilities or handicaps?".

6. TEST OF SCREENING MECHANISMS

The three Statistics Canada screening tests used combinations of these approaches. Also persons aged 15 or over were administered a different questionnaire than those under 15 years of age. No suitable set of ADL's has been compiled for children. In fact, most disability surveys that have been previously conducted have excluded children. Here, we will consider only persons aged 15 years and older.

In the November 1983 Labour Force Survey, each respondent was asked "Does ... now have any disability or handicap which has lasted or is expected to last six months or more?" This was called Test 1. Persons screened in by this question were those responding "yes".

The other approaches to screening were tested using two different questionnaires each administered in the January 1983 Labour Force Survey. These questionnaires were called Test 2 and Test 3.

Test 2 included the following sections: a list of special aids, a list of ADL's, and the activity limitation question "Are there any (other) conditions or health problems that now prevent or limit ... when carrying out his/her normal daily activities at a job, in school, or in the home? Please report only difficulties which are expected to last more than six months?". Persons who reported using at least one of the special aids or having trouble doing at least one of the ADL's or who answered "yes" to the above question were screened in.
Test 3 included a list of ADL's, a list of chronic conditions, and the following two work disability questions: "Is . . . limited in the kind or amount of work he/she can do at his/her job or business because of a long-term physical condition or health problem?" (asked only to employed persons) and "Is . . . prevented or limited in the kind or amount of work he/she could do at any job or business because of a long-term physical condition or health problem?". Persons who reported having trouble doing at least one of the ADL's or who had at least one of the chronic conditions or who replied "yes" to either of the above two questions were screened in.

Lists of the special aids, the chronic conditions, and the ADL's used in these tests are given in the appendix. It should be noted that the ADL's used in Test 2 and Test 3 were identical although slightly modified from the OECD list. In addition, each test takes a different approach to the ADL list. Test 2 permits the use of aids to perform the activities, while Test 3 does not.

These proposed screening methods do not permit an assessment of whether or not the target population is being correctly identified, unless they are used on a control population. This has not been done for the Canadian survey.

Test 1 was administered to all persons in households in the November 1982 Labour Force Survey. In January 1983, two rotation groups were used for each of Test 2 and Test 3. These rotation groups were chosen so that each in-sample household had also been in-sample in November 1982. This facilitated the comparison of the results of Test 1 with those of Test 2 and Test 3.

6.1 Major Findings of the Pilot Tests

The major goal in the analysis of the tests was to determine the set of questions that would be most effective in screening in those persons who belong to the target population. Another important factor was to determine an effective screen that would also not unduly increase respondent burden or cost. In addition, sources of non-sampling errors that became evident during the analysis were noted so that, for example, survey procedures or questionnaire design could be changed appropriately. The following discussion presents the major findings of the analysis.

The sample size for Test 1 was about 115,000 persons. For each of Test 2 and Test 3 the sample size was almost 38,000 persons. For all three tests the samples were about 49% male and 51% female.

Table 1 shows by sex the percentage of the sample screened in by Test 1, Test 2, Test 3 and by each section of Test 2 and Test 3. Most notable in this table is that Test 1 screened in only 5.6% of the sample as compared to about 16% of the sample for either of the ADL questions. Given that functional limitation as measured by the activities of daily living is a key indicator of disability, this shows that the single question asked in Test 1 is not effective for screening in the entire target population.

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
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<tbody>
<tr>
<td>Percent Screened in by Each Section of Each Questionnaire, by Sex</td>
</tr>
<tr>
<td>Section</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Test 1:</td>
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<tr>
<td>Test 2: ADL</td>
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<tr>
<td>Test 2: Aids</td>
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<tr>
<td>Test 2: Activity Limitation</td>
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<tr>
<td>Test 2:</td>
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<tr>
<td>Test 3: ADL</td>
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<tr>
<td>Test 3: Work Disability</td>
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<tr>
<td>Test 3: Chronic Conditions</td>
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<tr>
<td>Test 3:</td>
</tr>
</tbody>
</table>
Percentages of the sample screened in by Test 2 and by Test 3 are shown by age in Figure 1. For both tests, the probability of being screened in is highly related to age. The probability of being screened in is an increasing function of age. Although the degree varies, the same relationship holds for each of the Sections of Test 2 and Test 3, for each of the seventeen ADL’s and for most of the chronic conditions (multiple sclerosis, epilepsy, cerebral palsy, cystic fibrosis and muscular dystrophy are exceptions).

Since functional limitation is a good indicator of disability the question for the analysis was how to include the ADL’s on the screen rather than whether to include them. The “with special aid approach” (Test 2) selected 15.5% of the sample while the “without special aid approach” (Test 3) selected 16.0% of the sample. The difference between these figures is not statistically significant. For both respondents and interviewers the “with special aid” concept seemed to be more natural and more easily understood and was therefore chosen for the finalized screen.

Since the complete set of activities can be used to obtain a measure of degree of disability, all seventeen ADL’s were retained for the finalized screen.

The special aids section in Test 2 screened in 3.0% of the sample. Of these, 84.2% were screened in by the ADL section. Thus although this type of data is of interest for the disability database, the aids section is not an efficient screening mechanism, especially in combination with the ADL section. Consequently, questions on aids are not included on the finalized screen.
In addition to activities of daily living, major activity limitation is also an important aspect of disability. The Test 3 questionnaire addressed this by the two questions noted earlier in this section. These questions, however, considered it only from the point of view of work disability. Of the persons in the Test 3 sample, 13.1% were screened in by these questions (6.8% of employed persons, 6.6% of unemployed persons and 22.7% of persons not in the labour force).

Although there were no obvious problems with the data from the work disability questions, there were some operational difficulties. In particular, the questions sometimes seemed irrelevant to retired persons. Thus, the finalized major activity limitation question was adapted in order to better suit persons not in the labour force.

The chronic conditions section in Test 3 screened in 23.9% of the Test 3 sample. Of these, 37.9% were not otherwise screened in. There were two main problems with this section. First, the question was difficult to answer for respondents who were not sure of the nature of their particular condition(s). Another difficulty is that the data sought on the follow-up questionnaire, are generally more pertinent to persons who are currently disabled. Thus persons screened in by a chronic condition, but not currently having a functional limitation or a major activity limitation would be interviewed for the follow-up and probably provide little useful data.

Given these problems, chronic conditions are not used as screening criteria on the finalized screen. One exception to this is mental handicap. This one condition is retained as a screening item since there may be persons with mental handicaps who are not screened in by the ADL’s, or even by the major activity limitation question.

The project team felt that there would likely be differences in proxy and non-proxy responses related to any particular person. To increase non-proxy response, interviewers were instructed that whenever possible the questionnaire was to be completed by interviewing the individual to whom it applied. If a knowledgeable household member insisted upon responding for other household members, then this response was to be accepted; although the practice was to be avoided.

The level of proxy response obtained is considered to be fairly low (20.7% for females, 32.2% for males). Even after accounting for age-sex differences, it was found that proxy respondents were slightly less likely to be screened in than non-proxy respondents. Two reasons can be suggested as to why the probabilities of selection differ. First, persons who are unavailable and for whom proxy responses were provided may be less likely to be disabled. Second, proxy respondents may be less likely to state that a person has trouble doing an ADL or a major activity than the person himself/herself.

7. DATA REQUIREMENTS

As a result of a solicitation of data requirements from users, 173 responses were received which identified 588 issues of data needs. The following eleven areas were identified.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Number of users requesting data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nature of impairment</td>
<td>123</td>
</tr>
<tr>
<td>2. Demographic characteristics</td>
<td>95</td>
</tr>
<tr>
<td>3. Employment</td>
<td>85</td>
</tr>
<tr>
<td>4. Assistance</td>
<td>77</td>
</tr>
<tr>
<td>5. Education</td>
<td>50</td>
</tr>
<tr>
<td>6. Accommodation</td>
<td>45</td>
</tr>
<tr>
<td>7. Economic Characteristics</td>
<td>41</td>
</tr>
<tr>
<td>8. Transportation</td>
<td>29</td>
</tr>
<tr>
<td>9. Social activities</td>
<td>26</td>
</tr>
<tr>
<td>10. Health</td>
<td>9</td>
</tr>
<tr>
<td>11. Communication</td>
<td>8</td>
</tr>
</tbody>
</table>
The nature of impairment/disability/handicap is basic to the survey. Considerable detail is collected, including cause of disability. Most users of the data are interested in focusing on the impairment or disability groupings separately. Demographic characteristics are always important data as they allow the user to identify sectors of the population falling into different categories.

It can be easily understood that employment data about the disabled would be an important issue, as employment is a key component to the independent living of a disabled person. A great deal of employment data are already collected by the LFS. The follow-up survey will collect data related to employment limitations experienced as a result of the disability. In addition to the analysis of the data for the disabled population, these data will permit comparisons of the labour market characteristics of the disabled with those of the Canadian population as a whole.

Three aspects of assistance are considered: technical aids and skills, employment related assistance, and education related assistance. In all three areas, need for aids or assistance was deemed more important than was use. Under technical aids and special skills, interest is greatest for those aids and skills which are most prevalent, or for which special services or facilities must be provided. The aids would be grouped under hearing, speaking, seeing and mobility. Employment related assistance refers to the impact of aids on the ability of the disabled to work.

The LFS already determines the highest level of education achieved by each respondent. In addition, the follow-up survey will collect data on current educational activity and the impact of disability on current and past education.

The LFS collects information on the dwellings of the respondents. Additional accommodation data will be collected on special architectural/structural features, both inside and outside the home and other buildings.

Economic characteristics will be considered in the following areas: personal income including financial assistance received due to disability, sources of financial assistance, and special expenses incurred as a result of the disability.

Transportation data will be collected on three types of travel: travel to work or school, other local travel and long distance travel. Details on each area will identify the modes of transportation used, frequency of use and problems encountered due to the disability.

Although some interest was expressed by users in data on social/leisure activities, health and communication, no data will be collected for these issues by the present survey. For the first and third of these issues it was felt that reliable and useful data could not be collected in this survey. Questions related to health are also not included because of the already substantial response burden imposed by issues of higher priority.

8. RELIABILITY OF ESTIMATES FROM THE DISABILITY SURVEY

When determining the content of a questionnaire, consideration must be given to the reliability of estimates produced for the various data items. It is useless to collect data which will not be reliable enough to publish, even if the data requirement has a high priority. The reliability of an estimate is tied directly to the sample size. For this survey, the number of persons receiving a screening questionnaire is fixed. Therefore the reliability of the estimates produced will depend on the number of disabled falling into the sample and the prevalence rates of each characteristic of interest. Based on population projections from the 1981 Census of Population and certain assumptions it is possible to estimate minimum prevalence rates required to produce an estimate which is "reliable enough" to publish. An estimate whose coefficient of variation is less than or equal to 16.5% is considered releasable without qualification by LFS. Table 2 displays the expected minimum releasable estimates for the disability survey. Estimates of this size or higher will have coefficients of variation of less than 16.5%, subject to the validity of the following assumptions.
(1) All LFS sampled households are administered the screening questionnaire except the one-sixth of the sample which is in its first month of the survey,
(2) 2.95 persons per household on average,
(3) 5% LFS non-response rate,
(4) 5% disability survey non-response rate,
(5) Design effect of 2.5 (this accounts for the fact that a simple random sample design was not used),
(6) 19% of total adult population and 8% of total child population (aged less than 15) are screened in.

To explain the table in more detail, consider, for example the province of Newfoundland. An estimate of 9,000 persons possessing a particular characteristic will have a coefficient of variation less than 16.5% and is publishable whereas an estimate of 7,000 will have a coefficient of variation greater than 16.5% and is not publishable. An estimate of 8,000 is approximately 1.4% of the population of Newfoundland. Given the assumptions about percentage disabled in the population, an estimate of 8,000 is approximately 10.1% of the adult disabled population and 59.1% of the child disabled population of Newfoundland.

The design effects observed from Test 2, Test 3 and the October 1983 Disability Survey for number of persons screened in were about 1.5. This suggests that design effects for number of screened in persons with specified characteristics are probably also much less than 2.5.

In the October 1983 Disability Survey 12.9% of adults and 4.8% of children in the sample were screened in.

Table 2
The expected minimum releasable estimates

<table>
<thead>
<tr>
<th>Province/Region</th>
<th>Min Pa</th>
<th>Min Xb</th>
<th>Min Dc</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Adults</td>
<td>Children</td>
</tr>
<tr>
<td>Atlantic</td>
<td>0.4</td>
<td>7,500</td>
<td>2.3</td>
<td>16.2</td>
</tr>
<tr>
<td>NFLD</td>
<td>1.4</td>
<td>8,000</td>
<td>10.1</td>
<td>59.1</td>
</tr>
<tr>
<td>PEI</td>
<td>2.9</td>
<td>3,500</td>
<td>20.0</td>
<td>&gt;100</td>
</tr>
<tr>
<td>NS</td>
<td>1.1</td>
<td>8,500</td>
<td>6.9</td>
<td>54.5</td>
</tr>
<tr>
<td>NB</td>
<td>1.0</td>
<td>7,000</td>
<td>6.7</td>
<td>49.5</td>
</tr>
<tr>
<td>Quebec</td>
<td>0.5</td>
<td>30,500</td>
<td>3.3</td>
<td>28.2</td>
</tr>
<tr>
<td>Ontario</td>
<td>0.4</td>
<td>32,500</td>
<td>2.6</td>
<td>22.0</td>
</tr>
<tr>
<td>Prairies</td>
<td>0.3</td>
<td>10,000</td>
<td>1.7</td>
<td>12.4</td>
</tr>
<tr>
<td>MAN</td>
<td>0.9</td>
<td>9,000</td>
<td>7.0</td>
<td>47.6</td>
</tr>
<tr>
<td>SASK</td>
<td>0.8</td>
<td>7,000</td>
<td>5.0</td>
<td>38.0</td>
</tr>
<tr>
<td>ALTA</td>
<td>0.6</td>
<td>13,000</td>
<td>4.1</td>
<td>29.9</td>
</tr>
<tr>
<td>British Columbia</td>
<td>0.7</td>
<td>17,500</td>
<td>4.4</td>
<td>38.2</td>
</tr>
<tr>
<td>Canada</td>
<td>0.1</td>
<td>18,000</td>
<td>0.6</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Pa = minimum estimable percentage of the total population,
Xb = minimum estimable total,
Dc = minimum estimable percentage of disabled adults or children.
APPENDIX

Special Aids
Does . . . now use
   a wheelchair?
crutches or other walking aids?
any kind of brace excluding braces for teeth?
medically prescribed orthopedic shoes?
artificial limb(s)?
a hearing aid?
a guide dog?
a white cane?
any other kind of special aid?

Activities of Daily Living
Does . . . now have any trouble
walking 400 metres without resting (about 3 city blocks)?
walking up and down a flight of stairs?
carrying an object of 5 kg. 10 metres (e.g. carrying a 12 lb. bag of groceries 30 ft.)?
moving from one room to another?
standing for long periods of time (e.g. more than 20 minutes)?
when standing, bending down and picking up an object from the floor (e.g. a shoe)?
dressing and undressing himself/herself?
getting in and out of bed?
cutting own toenails?
using fingers to grasp or handle?
reading?
cutting own food?
reading ordinary newsprint (with glasses if normally worn)?
seeing clearly the face of someone from 4 metres (e.g. across a room)
(with glasses if normally worn)?
hearing what is said in a normal conversation with one other person?
hearing what is said in a normal conversation with at least two other persons?
speaking and being understood?

Chronic Conditions
Which, if any, of these long term conditions or health problems does . . . presently have?
   heart disease
   kidney disease
   lung disease
   cancer
   diabetes
   epilepsy
   cerebral palsy
   multiple sclerosis
   cystic fibrosis
   muscular dystrophy
   paralysis of any kind
   arthritis or rheumatism of a serious nature
   high blood pressure
   hearing trouble (uncorrected by aid)
   vision trouble (uncorrected by aid)
   mental handicap
   any missing limb(s) including finger(s) and toe(s)
   any other long-term condition or health problem (please specify)
REFERENCES


